

Helping Alzheimer's patients stay independent

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Family members or professional caregivers who do everything for older adults with Alzheimer's disease may just be wanting to help, but one University of Alberta researcher says that creating excess dependency may rob the patients of their independence and self-worth.

U of A psychologist Tiana Rust, who recently completed her doctoral program, says her research indicated that caregivers adopted a "dependency support script," assuming control of tasks they believed patients seemed no longer capable of doing for themselves. She says this model shows that the caregivers' beliefs, rather than the person's real abilities, drove their interactions with the patients. Her research also showed that the caregivers' actions were also seemingly incongruous with their values of wanting to treat patients with respect and promote their independence.

With an aging Canadian population, the number of people suffering from the disease is expected to increase over the next 20 years, she says. Thus, changing behaviour becomes critical—and she's hoping her U-of-A based research will help spark that change.

"When we create this excess dependency that doesn't need to be there, this is a problem," said Rust. "1.1 million Canadians are projected to have dementia by 2038. So, if we're able to maintain and promote independence to the degree permissible by the disease, that's important."

Help not necessarily wanted

Rust observed several caregivers and Alzheimer's patients in an experimental setting where they were asked to prepare a meal together. What she found was similar to behaviour patterns found in other studies with [older adults](#): caregivers would assume responsibility for tasks that they believed patients were incapable of doing on their own. However, she noted that caregiver actions were not always based on their observations of the patient, but sometimes on their own beliefs.

"The caregivers who believed that people with Alzheimer's disease in general are more likely to be at risk for injury and are more accepting of help were more likely to be dependence supportive than independence supportive," said Rust. "This suggests that caregivers are basing their behaviours partially on their beliefs rather than basing their behaviours on the actual needs and the actual abilities of the people that they're interacting with."

Help them to help themselves

Rust said that in followup interviews, caregivers noted that they placed importance on treating people with Alzheimer's disease with respect and promoting their independence. Yet, she noted that the caregivers' actions did not always follow these goals or desires. She recounted the story of a lady whose husband suffered from Alzheimer's disease. The man attended a day program at a nursing home, where he would take on a number of tasks that his wife had assumed for him at home. Rust said the woman was surprised that he was still able to perform these tasks as he had not done them in months at home. It's an example, she says, of gauging the person's abilities rather than making an assumption about the person's ability based on societal beliefs related to the disease.

"People with Alzheimer's disease have varying abilities, so it's important to base [caregiver] interactions on the actual abilities of the person," she said. "Observing the person and gauging what they're capable of before jumping in and supporting the dependence of the person is definitely important."

Training a critical component for both parties

Rust said that training for caregivers, to provide them with better understanding and proper tools that help them base their interactions with people with Alzheimer's on the actual abilities of the person, could alleviate the potential for unnecessary intervention that would bring about patient dependence. Teaching them to observe and assess the person's actual needs through interaction and observation, rather than what they believe the person needs, is vital in maximizing the person's independence for as long as possible. One way, she says, is to assist the person by breaking up tasks such as preparing a meal into smaller, more manageable tasks that they can accomplish using verbal cues.

"The task we had given the caregivers and the residents to do was set the table, make grilled cheese sandwiches, mix juice and clean up afterwards. All of those tasks are quite big in themselves, but they can all be broken up into small activities," said Rust. "These are all small tasks that these people with Alzheimer's disease were still capable of doing even though they might not have been able to do the full task."

"It's a hard role as a caregiver to try to gauge what the person can do, to know what the patient is capable of, how much they can break up these tasks. But these were all things that the [caregivers](#) mentioned in the interviews, so they're definitely wanting to promote the independence of these residents."

Provided by University of Alberta

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